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Science in Culture

Exploring the reciprocal relationship between the sciences and the arts and humanities and suggesting new avenues for cross-disciplinary innovation



Arts & Humanities
Research Council

BANKING (ON) THE BRAIN: The Neurological in Culture, Law and Science

Dr. Shawn H.E. Harmon

(with thanks to the Project team for their helpful contributions)

Executive Summary (198 words)

Through cross-disciplinary investigations and discussions around the governance of brain-banking (BBing), this Project (AH/J011495/1) explored interactions between science and culture, addressing questions pertaining to conceptions of the brain embedded within BB practice, the impacts of these on law, and the legal and cultural traction of the knowledge produced by BBing. This Project found that the brain is salient in legal debates around death and injury compensation, but it is treated like any other tissue/organ when it comes to science regulation. BBs are governed by de jure law and de facto regulation emerging from routinized practice and codes of conduct. Despite resonance of issues and concerns between BBs and other types of biobanks, dialogue about the ethical, legal and cultural aspects and implications of the work in these domains remains limited. More broadly, neurologic knowledge is contributing to the development of 'neurolaw' – a discursive realm within which there is often a poverty of understanding of both the scope and limits of neuroscience and BBs, and the practice and meanings of law. Regarding collaboration, this Project shows how the ambiguities and ambivalences that differences between intellectual traditions might produce can be leveraged to animate new interdisciplinary conversations, initiatives, and innovations.

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Key words

Brain banking – biobanking – governance – regulation – law – culture – neuroscience –
humanities

Summary Report

Key Findings, Outcomes, Outputs and Lessons Learnt (1,009 words)

Key Findings

Through cross-disciplinary investigations/discussions, the Project explored A&H and scientific interactions and the governance of BIng. Structuring questions and findings:

1. To what extent does science reflect A&H conceptions of the brain?

The brain has been an object of inquiry for centuries. Views of the importance and function of the brain have changed: Galen considered it a set of cavities occupied by animal spirits; Descartes was more concerned with the mind, consciousness and the soul; he was critiqued by those who framed the brain as an anatomical object. Mid-18th century scholars associated brain function with thought and electricity. Mid-19th century scholars began isolating parts of the brain associated with specific functions (speech). Modern BIng is reflective of the 'biomedicalisation' of society, a phenomenon advanced by the medico-scientific complex and popular desires for deliverance from all manner of conditions and states-of-being.

Although A&H and cultural representations of the brain do not obviously influence scientific practitioners, A&H conceptions have exerted a subtle influence on scientific thinking about the brain. What has emerged from their long-time interaction is a conception of the brain as the seat of 'self' (brain function is conflated with 'self'). Neuroscience, of which BIng is a component, draws on the dominant medical paradigm of 'disease': physiological malfunctions can be separated from the person, causatively identified, and symptomatically relieved. BIng also adopts/advances the primary scientific ideology of atomism: the idea that we learn about nature and ourselves by reducing the object of study to its smallest components. Indeed, advances in imaging are leading to claims that it may be the 'gorse' of neural connections that are key.

2. To what extent do these conceptions shape the law?

Perhaps surprisingly given the sociological/cultural importance attributed to the brain, the brain has not featured strongly in legal scholarship. It has been the subject of debate regarding brain stem death, and its importance is reflected in awards for brain injuries, but it is treated like any other tissue/organ when it comes to regulation of science. UK legislation does *not* explicitly mention the brain, and the law has mostly remained steadfastly focused on the self (as subject) rather than the brain (as object); it focuses on capacity and vulnerability and the need for conscious reflection. It resists the neuroscience fixation on brain as self by continuing to rely

on 'illnesses of the *mind*', which permit wider sources of evidence than brain structure/function evidence.

3. To what extent might scientific knowledge impact on popular understandings of the brain and/or inform/influence the law?

Scientific metaphors associating the brain with machinery, particularly computers, and modularity, are dominating popular representations. Images of brains held in hands, bandaged brains, brains inserted with usb sticks are common. But genuine public understanding of neurologic knowledge is questionable, partly because it is the more radical and contested claims that are most widely disseminated. Claims that challenge principles fundamental to the law include claims that neuroscience will:

- demonstrate that 'we are our brains';
- alter conceptions of rationality and free will;
- permit technological/technical assessment of truthfulness/guilt;
- allow the measurement of intellectual functionality;
- prove the existence of 'dangerous minds'.

Such claims exert a strong influence on public expectations and demonstrate that debates around 'neurolaw' need further and improved input from A&H.

With respect to the regulation of BBs, we found:

- BBing is governed primarily by the *Human Tissue Act 2004* (England, Wales, Northern Ireland) and the *Human Tissue Act (Scotland) 2006*.
- The HTA 2004 erects a licensing scheme with which BBs must comply. The HT(S)A 2006 does not, but Healthcare Improvement Scotland has recently erected a non-statutory accreditation system designed to demonstrate the 'highest possible professional standards'.
- The HTA 2004 relies on 'consent' whereas the HT(S)A 2006 relies on 'authorisation'. The latter is seen as a departure from passive acceptance; it is more active, reflecting the idea that consent for unspecified future studies cannot be 'informed' and is not properly 'consent'. Both consent/authorisation form characterises donation as a 'gift'.
- In practice, these divergences make no difference; practices are not standardised, but they *are* harmonised, a primary motivation being to facilitate tissue sharing within the UK.
- BBs in both jurisdictions are members of, and work to standards agreed by, the MRC Brain Banks Network, which formulates common policies and procedures so as to

ensure high standards of operation. Its Codes, combined with actor practices, produce a governance framework that exceeds hard law: statutory provisions around consent/authorisation are very specific, placing decisional power with donors. However, practice more closely follows guidelines and the practicalities of promoting respect and harmony between doctor/nurse and patient/family. Thus, whilst legislation offers no veto for relatives of a deceased who has consented/authorised to the use of his/her brain/tissue, the Code urges caution, stating that the impact of going ahead in light of familial opposition should be considered (and BBers never proceed in the face of family discord).

- BBs must obtain approvals from NHS Research & Development *and* relevant Research Ethics Committees. REC oversight tends to focus on issues of consent/authorisation, compliance of use with originally claimed/anticipated purposes, and third party access, which is also addressed by the Acts. While BBers cannot monitor how (foreign) researchers handle tissue or data provided from UK BBs, BBers come to know regular users and their practices/legislation.

There are ELSIs relevant to BBinng that reflect those in other forms of banking (eg: procurement, storage, access, unknown purpose), but there appears to be little dialogue between such banks.

Outcomes/Outputs

Reports To:
AHRC (01/10/12)
MI website
Network website
SCRIPTed (01/12/12)
Network
STIS Newsletter
Participants (01/10/12)
Articles To:
<i>Sociology</i>
<i>Law, Innovation & Technology</i>
<i>Journal of Medical Ethics</i>
Chapter:
<i>Technoscience, Law and Society: Interrogating the Nexus</i>
Public Lecture:
Bioethics Film Festival
Presentations:
Manchester Museum (20/03/12)
World Congress of Psychiatric Genetics (16/10/12)
American Network of Neuropsychopharmacology (03/12/12)
Capacity:
Career development for RFs

Lessons Learnt

Although different disciplines evince different epistemological and ontological disjunctions, even within A&H traditions, it is important to articulate perspectives and foster debates between disciplines. Unless debates are joined and disjunctions identified and interrogated, the social picture will remain incomplete and misunderstandings and confusion will persist. Encouragingly, the ambiguities and ambivalences to which differences give rise can be leveraged to animate new kinds of interdisciplinary conversations, initiatives, and innovations.

Collaboration and Partnerships (446 words)

This Project was a collaboration between the J Kenyon Mason Institute for Life Sciences, Medicine and the Law (MI) and members of the MRC Brain Bank Network (Network). Both partner organisations benefitted from the interactions enabled by this Award. In particular, it allowed them to engage in debates beyond those which dominate the primary disciplines represented by these organisations. It also facilitated more wide-ranging critical reflection on the knowledge-making practices within both the sciences and the humanities, and how and to what extent they co-develop.

The Project afforded the partner organisations the opportunity to collaborate with, and solidify ties to, a range of scholars and organisations across the University of Edinburgh, and the diversity of those ties is demonstrated by the list of partners in this new network (above), which encompasses over a dozen organisations across the sciences and humanities. The Project also directly facilitated ongoing collaborative work on BBing with international partners, including:

- Prof. Thomas Schulze, MD, Georg-August-Universität, Germany;
- Dr. Peter Falkai, Georg-August-Universität, Germany;
- Dr. Francine Benes, MD, Harvard University, USA;
- Thomas Insel, NIH, USA;
- Joel Kleinman, NIH, USA;
- Daniel Lightfoot, Autism Speaks, USA;
- Dr. Camilla Stoltenberg, Norwegian Institute of Public Health, Norway.

The new MI-Network partnership fostered through this Award will serve as an important platform for future innovative research at the interface of science and culture, and will offer the opportunity to explore new questions and design new communication methods. It will also help inform future developments for the Network, including a donor forum, which is proposed to help address future needs for brain donation, particularly around dementia research, which research was identified as a priority in the Prime Minister's challenge on dementia for 2015.

As a direct result of this Project, ancillary research has been conducted and is being planned. With respect to research already conducted, one Co-I (Haddow) and an RA outwith the Project conducted 70 interviews with members of the public at the Wellcome Trust exhibition, 'The Brain as Matter' (15 June 2012). Findings are currently being analysed with particular conceptual areas being (1) the status of the brain, (2) issues around brain donation, and (3) reactions to the exhibit itself (thoughts and feelings). Data will be shared with the Project team and this research may evolve into a further collaborative funding proposal on organ and brain donation which would involve not only BBers, but also tissue/DNA bankers and DNA databankers. With respect to research being planned, our work on this Project has contributed to MI securing international funding to establish a Neurolaw Network in Edinburgh in association with MI. Funding of the Neurolaw Network will commence in 2013 and will support RAs which will facilitate further research and network strengthening.

Future Research Opportunities (498 words)

In addition to research already planned and supported (see above), including the new Neurolaw Network, the Project uncovered several examples of 'science in culture' questions relating to BBring that deserve further investigation:

1. **Incidental Findings:** Increasing reliance on imaging technologies increases the possibility that findings of potential diagnostic importance will be made in research, thus raising the issue of 'incidental findings' (findings not central to the project for which the brain was scanned). Policies on feedback to participants have yet to be agreed. In addition to surveying the legal/regulatory position, research needs to explore practices amongst BBers, public perceptions/expectations, the position of individuals re the 'right not to know', and the position of those confronted with a relative identified as having a particular brain type (a 'psychopath's brain').
2. **Brain Sourcing:** Given the inconsistencies identified, the interface between legislative framework and brain donation practices demands closer investigation. While it is hoped that the appointment of a Chief Coroner will promote common policies aimed at realising the wishes of donors and their families whenever possible, practices and views around sourcing remains a pressing concern. Questions are: What processes for obtaining consent (especially from those with 'diseased brains') are used? To what extent do uneven practices re obtaining a death certification and notifying the Coroner/Procurator Fiscal prior to retrieval introduce unnecessary delays or complete bars to procurement, and how does this impact on families.
3. **Stewardship:** Another understudied issue is that around international distribution of tissue and how BBers can ensure ethical standards are met in foreign facilities which may be sharing resources with or from UK BBers. This is a very practical question which has profound consequences for claims to ethical practice and transparency, and, ultimately, to trust.

4. Motivation: Religion, conceptions of the mind and soul, and misunderstandings about how science is conducted colours expectations and positions taken toward donation/participation. There is a dearth of socio-philosophical research on the role of religion at each stage and on each stakeholder in BBing, and how public expectations are formed. Interdisciplinary research and public engagement activities/research needs to explore these questions and fashion a methodology for improving communication.

A further question relating to 'neurolaw' more broadly was raised: Some of the literature makes bold claims about how neuroscience will 'revolutionise' the law and necessitate radical reform. This literature and its effect on public expectations should be critically examined, as should current and potential *practical* uses of imaging evidence. Open questions include: Might neuroscience encourage socially desirable behaviour, and how? Should neuroscience evidence be proof of mitigating circumstances, and in what types of cases? If, as claimed, imaging evidence can seem more 'real' than witness accounts of an individual's disposition, how is it most justly deployed bearing in mind that it is interpretable (note the very different interpretations the experts took in relation to a scan in Carr v Thomas (2008))? A deeper and more interdisciplinary look at how the justice system should be called upon to use this evidence is warranted.

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